

Title	A qualitative analysis of the efficacy of the Rainbow Club Cork Centre for Autism
Authors	Lynch, Paddy
Publication date	2020-05
Original Citation	Lynch, P. (2020) A qualitative analysis of the efficacy of the Rainbow Club Cork Centre for Autism. Cork: Community-Academic Research Links, University College Cork.
Type of publication	Report
Link to publisher's version	https://www.ucc.ie/en/scishop/rr/
Rights	©2020, Paddy Lynch.
Download date	2023-05-05 02:56:11
Item downloaded from	http://hdl.handle.net/10468/10967

A Qualitative Analysis of the Efficacy of the Rainbow Club Cork Centre for Autism

Paddy Lynch

CARL Research Project

in collaboration with

The Rainbow Club Cork Centre for Autism



Name of student(s):	Paddy Lynch
Name of civil society organisation/community group:	The Rainbow Club Cork Centre for Autism
Name of community group liaison person:	Karen O'Mahony CEO
Academic supervisor(s):	Dr Sharon Lambert
Name and year of course:	MA Psychology: AP6153 Applying Psychology in Community-Based Settings Placement
Date completed:	May 2020

What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the UCC website?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <http://www.ucc.ie/en/scishop/completed/> [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland. <http://carl.ucc.ie>. You can follow CARL on Twitter at @UCC_CARL. All of our research reports are accessible free online here: <http://www.ucc.ie/en/scishop/rr/>.

CARL is part of an international network of Science Shops called the Living Knowledge Network. You can read more about this vibrant community and its activities on this website: <http://www.scienceshops.org> and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

Are you a member of a community project and have an idea for a research project?

We would love to hear from you! Read the background information here <http://www.ucc.ie/en/scishop/ap/c&vo/> and contact us by email at carl@ucc.ie.

Disclaimer

Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group.

Abstract

In light of recent changes to diagnostic criteria and increased knowledge around the subject, Autism Spectrum Disorder (ASD) has become far more prevalent in society over the last two decades. For children who are diagnosed, ASD causes difficulties in communication and developing relationships and can have a profound effect on one's ability to function in the world around them. It can also be a huge burden for parents both emotionally and financially, as treatment and therapies can be extremely costly. Furthermore, children with ASD often receive diagnoses of other disorders, such as anxiety disorders. The Rainbow Club Cork Centre for Autism (RCCCA) was founded in 2015 in response to the lack of services at the disposal of families with a diagnosis of ASD. It runs social groups for children, as well as therapies such as speech and language therapy and occupational therapy for example. It also aims to help families through parental support groups. This study seeks to use thematic analysis to evaluate the quality of the service being run and ways it can improve in the future. One employee of the RCCCA, a former service user with ASD, and a mother of a child with ASD who attends the club were interviewed. The themes identified show the major social and personal benefits children avail of from the club as well as the great sense of community which helps children and families to thrive. However, the restrictions being placed on the club financially are significant and are holding the club back somewhat. In all, the service offered by the club is highly satisfactory and backed by research, but the growth of the club from this point forward is reliant on further funding being made available.

Introduction

Autism, as detailed by the American Psychiatric Association in the fifth edition of the Diagnostic and Statistical Manual for Mental Disorders, or DSM-5 (2013), is characterized by the persistent existence of deficits in social communication and social interaction, along with restricted and/or repetitive behaviour, as well as difficulties with socioemotional regulation. According to a report published by the Department of Health (2018), conducted using a number of worldwide and national studies on the prevalence of autism, it is estimated that autism spectrum disorder (ASD) affects approximately 1.5% of the Irish population. This reflects the results reported in an in-depth study of the statistics surrounding ASD prevalence in Ireland by Boilson et al. (2016). These numbers are somewhat controversial due to the rather ambiguous and oft changing diagnostic criteria used throughout the years for ASD in different editions of the DSM. The estimated prevalence rate of autism has risen in the last number of decades due to increased knowledge of the disorder and thusly a broader diagnostic criterion being used (Newschaffer et al., 2007). On top of this, there has been increased rates of diagnoses of ASD amongst girls, in the wake of much research in recent years with regard to a female protective effect which had previously led to a discrepancy in the number of girls being diagnosed (Duvekot et al., 2017). Due to such recent discoveries and continued research on the rates of autism worldwide and indeed in Ireland, the rate of 1.5% has been settled upon in recent years (Department of Health, 2018).

Along with the problems directly associated with ASD, such as the aforementioned social difficulties, frequent distress etc., there are a number of other issues which may arise for families of children with autism which can lead to a number of emotional and of course financial burdens which can be difficult to overcome. Firstly, there is a high rate of comorbidity in diagnoses of psychiatric disorders for children with autism which can

compound impairments that are already experienced by the child. A wide range of comorbid disorders are reported at very high levels. Approximately 70% – 72% of children with autism receive a diagnosis of at least one further co-occurring psychiatric disorder. Of these the most commonly present are anxiety and mood disorders, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), and oppositional defiance disorder (ODD). Additionally, there has been found to be high rates of other conditions among children with a diagnosis of ASD, namely post-traumatic stress disorder (PTSD), eating disorders, and gender dysphoria (Rosen, Mazesfsky, Vasa & Lerner, 2018).

However, there are a number of effective methods which can be used in order to help minimize the impact of ASD on a child's life. Weitlauf et al. (2014) carried out a review of previous research and showed the uniquely positive effects of numerous different therapies and interventions. Speech and language therapy, occupational therapy and interventions aimed at improving social skills have frequently been used to great effect to improve the lives of children with autism (Weitlauf et al., 2014).

Other factors that can buffer against the potentially negative impact a diagnosis of ASD can have on the child and their family is mental health, quality of life and social support levels. Results of a piece of research on the effects of having a child with autism, undertaken by Gau et al. (2012), comparing 151 families with at least one child with autism and 113 families of typically developing children in Taiwan, showed that both mothers and fathers of children with ASD suffered from increased rates of psychopathology than parents of neurotypical children, with the risk for mothers being more pronounced. In addition, it was detailed that parents of children with autism are less likely to agree on pertinent issues within their relationship. The study also revealed that mothers of children with autism reported less marital satisfaction, lower levels of affection expression and less family adaptability and cohesion than mothers of typically developing children. Parental mental health related quality

of life has been shown to be of substantial significance in the betterment of the symptomology of a child with autism, and allows for families to provide better care for their child and experience less parental stress. Hence, it is a salient need to find ways in which parental mental health related quality of life can be enhanced. Hsiao (2016) researched the impacts of numerous variables on parental mental health related quality of life and how they interact with one another. Crucially, it was found that neighbour support had a significant, positive impact on parental mental health related quality of life directly, but also indirectly via the positive impact neighbour support had in improving children's performance in school and social environments, in turn reducing parental stress, thereby further increasing parental mental health related quality of life. This study highlights the uniquely positive influence of strong communal social support, as stated explicitly by the author, – “The importance of support for parents of children with autism is critical” (Hsiao, 2016; p.129).

Furthermore, typically developing children with a diagnosis of autism can be impacted and may be in need of care and support in order to adjust to the aforementioned strains which are caused. A recent study by Jones et al. (2019), found that sibling adjustment and the sibling relationship worsens for typically developing children when their sibling(s) with ASD have greater levels of behavioural difficulties. However, it was found that for typically developing siblings with outlets for coping and support, their relationships with their diagnosed siblings were perceived more favourably, and their adjustment was more beneficial. This outlines a need for support for any neurotypical siblings in families with a child with ASD to be of a high priority.

The financial burden associated with effectively caring for and holistically nurturing children for families with a diagnosis of ASD cannot be underestimated. This has been demonstrated in the research of Roddy and O'Neill (2019), which shows the average cost per year per child for families of children with autism in Ireland between the years 2014/2015

(this being the latest figures available at the time the research was conducted) was €28,464.89. In contrast, the average yearly spend of the state per child with ASD was only €14,192.

Clearly the research cited above shows the emotional, mental and financial strain which is currently being placed on families in Ireland with children who have received a diagnosis of ASD. It highlights the need for a community based approach which prioritises the needs of diagnosed children, but also focuses on supporting families, especially mothers, who are coping with the tribulations of raising children with ASD.

The Rainbow Club Cork Centre for Autism (RCCCA) was first opened in June 2015, founded by CEO Karen O'Mahony and her husband Jon O'Mahony (The Rainbow Club for Children with Autism, 2020), who struggled with the lack of resources available in Ireland for children with autism. The RCCCA started out with 26 children availing of the services on a weekly basis. That number has risen to 418 children per week, as of February 2020 (The Rainbow Club for Children with Autism, 2020). The club has grown to provide a wide range of supports and therapies for children, such as speech and language therapy, occupational therapy, art therapy and play therapy along with music, sport and social groups, all of which have been shown to provide significant benefits for children with autism. However, the Club also offers familial support through parent support groups (The Rainbow Club for Children with Autism, 2020).

Evidently, the RCCCA provides a number of crucial services for children and families which have been shown by past research cited above to be of substantial benefit. The RCCCA is run entirely in a voluntary manner, without any state funding being provided, using independent fundraising events and subsidised charges for services provided to pay for all that is facilitated by the Club (The Rainbow Club for Children with Autism, 2020). Since the opening of the RCCCA's doors in June 2015, there has been no research done into the

efficacy of the services offered by the Club, nor has there been an analysis of the effects various aspects of the Club's services are having. The ambition of the RCCCA is to provide all of their services under one roof, whereby therapy rooms, a gym, social spaces, a sports hall etc. will be available in a single hub of education, care and support (Rainbow Club for Children with Autism, 2019). It is deemed that this will provide an integrated approach through which therapists, volunteers and employees can communicate with each other easily in order to maximise the efficacy of the service for the children. In addition, this expansion will allow for familial support groups to extend past just parents, to sibling support groups for typically developing children with siblings diagnosed with ASD. This plan will be discussed with participants and its potential value assessed.

The aim of this research is to deliver a qualitative analysis of the efficiency at which the RCCCA operates by interviewing three stakeholders each with unique viewpoints on how the Club has been run and the results it has provided for children and families who utilise the services the club affords. This will provide an insight into the strengths and weaknesses of the services offered to children and their families, and lastly highlight the opportunities which the RCCCA could avail of if they were provided with increased levels of state funding.

Method

Participants

In all, three participants were recruited to take part in the survey. Each of the three participants were selected as each could provide their own unique insights into the experience they have had in the RCCCA and the positive and negative aspects of the Club's work. The first participant interviewed was a 19 year old man who has been availing of the club's services since the age of 16, followed by a mother of a child with autism who attends the RCCCA twice a week for the club's sports morning every Saturday and one social group during the week. The third participant interviewed was an employee of the RCCCA who is tasked with providing care and support to children when they are in the Club for their weekly allotted time, as well as managing other employees and volunteers.

Procedure

Participants were first identified based on their knowledge of the RCCCA and the depth of information that they could provide in their interviews. They were then recruited and signed consent forms and were given information sheets detailing their rights throughout the collection of data. Each of the participants were then interviewed in a quiet room, one-on-one with the interviewer. A semi-structured interview was used in order to allow for the gathering of the specific data desired by the researcher in accordance with the aims of the study. A semi-structured interview schedule was deemed suitable in this case as it would allow for deviation from the script in order to delve into issues of pertinence to each interviewee which may not have arisen in each interview if a more restrictive, fully structured interview schedule was used. Each interview schedule was tailored slightly to account for the different perspectives each participant had on the club as a parent, former service user, and employee. Each interview lasted between 10 – 15 minutes and was recorded and later transcribed in full by the researcher for analysis.

Materials

As stated above, a semi-structured interview schedule was drawn up and utilised in the interviews. These interviews contained slightly different questions for each of the participants to account for the different parts of the RCCCA they make up (those being a parent, an employee and a former service user). For each participant, the interview schedules consisted of four open ended questions, one about what service users have gained through their involvement with the RCCCA, one about the specific programmes and events that are most beneficial, one about where improvements can be made in future, and a final question about the future plan to provide the services of the club under one roof as specified by the RCCCA (2019). A short interview schedule with open-ended questions was deemed sufficient in order to allow the interviewer and interviewee to discuss these three main concerns in detail, and provide concise information in relation to the research question. The interviews were recorded using the voice memo software application available on Apple iPhone 8 and subsequently transcribed using Microsoft Word software. Full copies of the interview schedules used are available below in Appendix A. Fully transcribed interviews are available in Appendix B, with coding also shown.

Data Analysis

Thematic analysis was used in this study in order to identify common points of interest and issues about the RCCCA brought to the fore by each participant. This was adjudged to be the best form of analysis as it would show themes which cropped up consistently despite the slight differences in experience with the club, thereby highlighting the most prominent strengths and weaknesses of the work carried out in the RCCCA. Initial coding was completed before the themes were identified which are detailed in the results below.

Ethics

All participants were made fully aware of their rights before the research was undertaken and provided consent to take part. They were also made aware of their right to withdraw their data after they had provided it within two weeks of the interviews being conducted, and were guaranteed full anonymity of the information given. In the transcripts of the interviews provided below in Appendix B, pseudonyms are given for each participant, as well as for all other people named throughout the interviews.

Results

Findings from carrying out a thematic analysis led to three major themes being drawn up. The first two themes are formed of two sub-themes each, while the final theme is a singular major theme. These themes were based on the high volume of discourse recorded across each of the three interviews conducted which all shared similar ideas and opinions as evidenced from the codes which were derived during the analysis. The themes are characterized and discussed below with quotes from each interview appended as examples of how these themes were constructed. The themes are labelled as “*Benefits for Children*”, “*Lack of Funding*” and “*Community*”. The interviewees are identified below as “Mother”, “Employee” and “Former Service User” denoting the mother of a child in the RCCCA who was interviewed, the employee of the RCCCA interviewed, and the former service user interviewed, respectively. Transcripts of each interview are available in Appendix B, below. Line numbers for each quotation examined are also provided.

Benefits for Children

The first major theme identified is described here as “*Benefits for Children*” and pertains to the clear improvements children attending the RCCCA are making according to the three interviewees. Two sub-themes emerged upon analysing the data; these were denoted as “*Social Benefits*” and “*Personal Benefits*”. Data which led to the construction of these themes is discussed below.

Social Benefits

Across all three interviews, there is clear evidence provided which substantiates the claim that the children who attend the RCCCA make huge strides in their social skills from the point of entry to the Club onwards. This is made abundantly clear in the examples given

by the Former Service User. He states that he himself went from being very quiet and having no desire to communicate with people around him when he first went to the RCCCA, to becoming very sociable and communicative.

Former Service User: “Eh, I would say I got a lot better with my social, sort of, skills. Before, like, I’d, I appear to be very social now but before, probably about five years ago, if you had approached me to ask me to do this interview, I wouldn’t have even had said no; I’d have sat in the corner in silence and ignored you.” (Lines 21 – 27)

Here, the progress made is clearly visible; evidently, it is a major leap for a child with autism to go from a place where they were almost non-communicative to a place where they are comfortable and deem themselves as being very social.

The Mother interviewed echoed these sentiments when talking about the strides her son has made since his introduction to the RCCCA. She discusses how the volunteers helped to encourage her son to speak and how to interact more suitably in specific social settings such as playing with other children.

Mother: “He was non-verbal when he first came to the Rainbow Club. Ehm, he had no social skills at all... he’s gained a lot of confidence in, ehm, interacting with other children and he’s come on leaps and bounds his speech ehm, he started speaking and the girls in the Rainbow Club, the volunteers, kind of worked with that, ehm, and they encouraged him to tune into playing, he’s now able to play with other children.”

(Lines 24 – 37)

Once again, we see evidence of a significant increase in social behaviour, from a base point of being non-verbal to now being able to play with other children. This is a profound leap in the right direction in terms of the child’s ability to communicate with those around him that he is able to speak to others and engage in play.

Finally, we get the perspective of the Employee. This interview didn't touch on this theme as flagrantly as the previous two. However, she describes of the comfort which the children feel when in the RCCCA. When discussing a particular child attending the club and availing of speech and language therapy, she states, "*she's so comfortable in the Rainbow Club it's like she's at home*" (Lines 149 – 150). This shows the ease at which children are able to socialise and engage with people in the RCCCA. As research shows it can be difficult for children with ASD to assimilate to different environments, so having a place where they can be with new people and meet other children while maintaining a high-level of comfort is clearly very helpful in improving social skills.

Personal Benefits

This sub-theme emerged frequently throughout the three interviews all in slightly different ways. It cropped up in relation to how the engagement children have in the club leads to greater self-confidence and increased ability to be themselves, thereby creating their own identity and sense of self; all through the services provided by the RCCCA. From the perspective of the Employee, it is significant for the children to have the social groups, and have a sense of ownership over them.

Employee: "I suppose the kids gain a social group, a place that's for them, it's their club, it's not... you know other children have ballet, have [sic]... whereas this is theirs. It's where they can be themselves and why they can socialize with their own peers." Lines (13 – 18)

Here, it is outlined that the Employee sees that the children have sense of empowerment in being able to have an outlet which is uniquely theirs. The nature of the social groups also means that they can be themselves in the club, which is obviously

important for children in their development. This is echoed by the Mother interviewed; *“he’s allowed be who he wants to be”* (Line 103).

The mother elaborates further on the benefits it has had for her child, in that he is more in touch with himself and has a better understanding of what he needs in certain situations.

Mother: “He kind of became more aware because he started at such a young age when he needed sensory breaks himself, ehm, with the volunteers in there encouraging him to use the sensory room. So now he actually knows already, he’s only eight, but he knows when he needs to withdraw from a setting and go into a sensory room.” (Lines 40 – 46)

Obviously, this is an essential skill for children with autism to learn and to pick it up at only eight years of age will be important for the child in the long-term as he develops into adolescence and adulthood.

Finally, the Former Service User details the improvements he made in himself since he entered the RCCCA in terms of how he views himself and his ability to communicate and engage with people around him, *“Confidence was definitely a big thing. I remember I was so nervous, when I first started that I had no idea what I was doing. Like, even, like I couldn’t do introductions or talk with people”* (Lines 54 – 57). Building confidence is key to dealing with the anxieties faced by children with ASD in terms of communication skills, and clearly from the example given by the Former Service User, the exposure to new people in a controlled manner in novel environments has aided him greatly, to the point where he now has a part-time job in the café ran by the club, *“They took over the café only last April, I believe. And I was volunteering in there, now I’m working in there”* (Lines 85 – 87). This also shows the manner in which the RCCCA endeavours to continue its support of former

service users, even after they turn eighteen and stop availing of the child centred services the club offers.

Underfunding

In each of the three interviews carried out, questions were answered regarding the most effective programmes and services offered by the RCCCA, the ways in which it can improve its services in the future, and about the strategic plan that the RCCCA is preparing to implement over the next few years of expanding its premises in order to allow for the distribution of all its services in one place. The responses to each of these questions were coded and the major theme “*Underfunding*” was constructed. Once again, two distinct sub-themes were identifiable upon characterization of the major theme, which are discussed below.

Spatial Restrictions

In many different ways, regarding many different topics, the issue of a lack of space was brought up repeatedly by each participant. This shows that it is clearly a salient issue that is holding the RCCCA back from being able to maximise its potential to help children and families with a diagnosis of ASD. The Employee highlights the ways in which the lack of space is restrictive in relation to the activities and services the RCCCA provides.

Employee: “This space here is limited, it’s very limited, like the speech and language therapist has a little Portacabin there, the play therapist and the art therapist share. I think like they’re aiming to have a specific music room, but whereas at the moment they’re using this room for music. Do you know, and then there can’t be a group run later in the evening in this room, because it’s music is in here.” (Lines 198 – 205)

In addition, when asked how the club can improve, she states that the limitations are causing waiting lists, which is obviously negative, as the club would like to reach as many children as possible, *“For this to become bigger, there’s so many children still on the waiting list”* (Lines 76 – 77).

The Former Service User echoes this sentiment, and agrees that the limited space the Club is operating under is harmful to its ambitions. However, from his perspective as a former service user, he believes that substantial financial aid is required, *“it feels like they need like ah... a massive push just to expand it. I feel like they do a lot and they do help with so much but where they are, they’re so limited in their resources”* (Lines 173 – 176). Of course, the children are the main benefactors of the services provided, so to hear that the club needs such help from this perspective is significant.

In addition to service users, parents are the other group targeted by the RCCCA to help. The Mother also describes how the lack of space is limiting the Club’s positive impact, and that all other parents involved in the Club believe expansion is critical, *“I suppose it’s what we all say; they need expansion, of course”* (Lines 143 – 144). In addition, the mother talks about how the lack of funding is preventing support from being provided to siblings.

Mother: “I have a brother myself on the spectrum and I know what it’s like growing up being the only sibling. And I think that’s a thing that’s overlooked sometimes, mothers and fathers are supported and sometimes, [sic] and the child is supported but the sibling is often forgotten about.” (Lines 164 – 170)

These quotes show that spatial restrictions is a prominent concern facing the Rainbow Club at present, and is of concern for all involved in the Club from the top down. It also details how siblings are missing out on potential support which cannot be provided under the current circumstances.

Need for Integration of Services

Across the three interviews, each participants' dialogue surrounding the lack of funding which is debilitating the RCCCA also touches on difficulties being caused by the absence of a structured approach which can incorporate the needs of every child in order to provide a better level of care for everyone involved in the service and allow for employees and volunteers to be able to carry out their work in a more proficient manner. In all three interviews, the key to improving the situation is to provide this integration by having services provided holistically and unilaterally, in line with the proposal the RCCCA has put forward to provide all of their services under one roof as is previously discussed.

For the employee, she states that her job is made more difficult by how children are forced to seek support from services such as speech and language therapy which are outside of the RCCCA's premises, and not being able to communicate with outside therapists is a disadvantage, *"The child would be out in a different area that I don't have access to or ask them how they're working with that child"* (Lines 184 – 186). She also states how the integration of the services in the club under one roof would help, *"For me it'll be a great benefit that I will have more access to the speech and language therapist, I'll have more access to the different areas that are going on"* (Lines 169 – 172). Increased communication can lead to a better service as communication between employees can help identify areas a child needs help with.

The Former Service User states that families are put under pressure due to the lack of funding not allowing for an ease of service which the RCCCA is trying to attain, *"Yeah, because I understand the pressure it puts on families when they have to be out here for like, say 2-3 for one child, and then they're not in until 5-6 for another session"* (Lines 206 – 289). The lack of funding is placing restrictions over how families can be catered for by the RCCCA, which in turn is placing pressure on families. He then explains the consequences of

these pressures and how having everything together can benefit, *“I’ve seen how some of the kids have meltdowns and it’s... I can see how much of a relief it could be to have it all together”* (Lines 294 – 296). The comfort and predictability of having an integrated service will lead to less distress for children and provide an easier environment for them to socialise with one another and for the employees to work.

The Mother reflects this stance on how such an ethos would be beneficial for children. She describes the troubles faced with seeking help from other services throughout the country and holds little confidence in the efficacy of such services given the lack of familiarity a child may have with novel practices in new environments, *“The child is going somewhere they’re not comfortable with as well, you know, so it’s just not going to work from the start”* (Lines 196 – 198). She then goes on to describe how having the service being provided from one location will help her as a mother, *“And then you have the parents then as well who will be around other parents, see familiar faces. You know, comforting for the parents too”* (Lines 206 – 208). This shows the convenience and comfort that the integration of the services will bring to everyone involved in the club.

Community

The final theme identified was labelled as *“Community”* which is in reference to the manner in which the RCCCA operates in an almost familial manner, with parents, children, employees and volunteers working together, collaborating and supporting one another in both a top-down and bottom-up manner. This sense of community is very tangibly evident throughout each of the interviews and is quite clearly a central part of the fabric of the RCCCA.

The support families and parents provide for each other is an essential part of the ethos the RCCCA seeks to work under. This is laid out clearly by the Employee in her

interview, when she describes how parental support groups work and what parents can gain from the time they spend with each other.

Employee: “If one person is struggling in one area another person might have went through it, like we have a lot of new parents coming on board at the moment that wouldn’t know where to go for help, who to ask for the help, the struggles with trying to get into schools, there’s so much unity with the parents; they’re giving each other advice, help, a shoulder to cry on as well.” (Lines 29 – 35)

In one passage, we see how the community spirit woven into the RCCCA comes out and can benefit parents, especially those to whom a diagnosis of ASD for their child can be frightening and bewildering. There is a clear culture within the Club for people to help one another.

The Mother testifies to this also, which is significant given her first-hand exposure to what the parental groups are like, and is clearly very appreciative of the amount of help and support she has been given during her time involved with the Club.

Mother: “It was very tough for me at the start. Ehm, with the Rainbow Club be-... [sic] you know, as soon as I got into the Rainbow Club, the parents in there; they like, just kind of took me in under their wing.” (Lines 62 – 66)

She speaks very highly of how other parents helped her and it can be seen that this was very much needed during the difficult times she faced when her son was diagnosed with autism. It mirrors and validates what was said by the Employee.

A further side to the communal nature of the RCCCA is described by the Former Service User. In his interview, he discusses how his experience in the RCCCA has led him to become a volunteer and that he has developed strong relationships with the children he now mentors, *“I’ve a good relationship with all the kids that are in that class because I’ve seen them for years now at this point”* (Lines 49 – 51). This shows how the RCCCA works as an

organisation, encouraging former service users to help younger, new children in the service and shows how they can operate as role models for these children. This theme highlights the warm and welcoming nature of the club, which is crucial in providing a satisfactory service for all stakeholders.

Discussion

The Rainbow Club Cork Centre for Autism (RCCCA) operates in order to provide care and support to children with a diagnosis of ASD, as well as their families. A number of different therapies and interventions are offered to children who attend the Club, and supports are given to parents in the form of parental support groups. The RCCCA plans to expand in the near future, with ambitions to provide a greater level of care and support to those who are part of the Club by providing all of their services in one complex operating in one location. The RCCCA outlines that this will allow for greater integration of services, and for the starting of new services such as counselling for parents, and sibling groups for siblings of children with ASD, in order to provide a more holistic and satisfactory service (The Rainbow Club for Children with Autism, 2019). The aim of this study was to obtain an evaluation of how well this service works and to what extent the services it offers are of benefit to children with ASD and their families, and to assess the consequences of the RCCCA's strategic plan for expansion over the next few years. There had been no evaluation of the service undertaken prior to this study. Interviews were carried out with an employee of the RCCCA, a former service user, and a mother of a child attending the club who is part of the parental support groups.

Results of the thematic analysis carried out gave rise to three major themes, two of which consisted of two sub-themes, which are of significance in terms of the evaluation of the service. The first theme of *Benefits for Children* details what children gain from the RCCCA. The first sub-theme is *Personal Benefits* and relates to how children who attend the club develop increased self-esteem and develop a more positive sense of self. Evidently the Club is a place where they feel comfortable and can be themselves. The second sub-theme, *Social Benefits*, refers to the greater social skills children attain from attending. These themes reflect benefits which are scientifically tangible, using interventions and therapies with

empirical research evidence to back them up, as shown by Weitlauf et al. (2014). The tangible benefits of attendance for children is undoubtedly a major strength of the RCCCA and, crucially, shows that it is achieving its most important objective.

The second most significant theme is characterized as *Underfunding*. Its first sub-theme (*Spatial Restrictions*) is prominent throughout the interviews and is brought up in many different ways in how the current buildings within which they are operating are holding the organisation back. Limited space is leading to increased waiting lists and restricting the activities and services that the children and families can partake in. The second sub-theme (*Need for Integration of Services*) illustrates the importance of having all of the services and therapies that are available at the RCCCA together to provide a holistic approach towards obtaining the goal of providing high quality care and support to service users. All three participants frequently state that they would prefer to have the service operate in such a manner. The participants agree that an integrated service will help with time constraints, dealing with anxiety the children may have with being forced to go to different services providers in different locations, and create a familiarity which is vital in creating a positive atmosphere for the children's growth. The past research also shows that the programmes that are planned to be installed along with this expansion, such as working with siblings and providing counselling services to improve parents' mental health, would be highly beneficial (Jones et al., 2019; Gau et al., 2012) In all, the theme of *Underfunding* highlights the limitations within which the RCCCA currently operates.

The third and final major theme is a singular theme, and is labelled as *Community*. This theme is perhaps the most significant to look at in terms of the evaluation of the services of the RCCCA as it shows a unique aspect of the club's ethos. Each in their own way, participants describe how the communal and familial side of the RCCCA is of benefit to service users, providing shoulders to cry on, building trust and friendship, and creating an

aura of hope and positivity that can often be missing especially for parents who may have been left shocked, confused and uncertain by a diagnosis. There is empirical research which also displays how having a strong community of support can be a huge advantage not only in improving children's lives, but by creating better lives for the families of children with a diagnosis of ASD (Hsiao, 2016).

With regard to the directions of future research, there are a few recommendations to be made. This study was the first of its kind looking into the work of the RCCCA, but it is advised that similar pieces of research be done with similar organisations who work with children with ASD and their families. It would be highly useful to see if similar findings are presented as any new information which may be provided would help to identify potential ways in which these different organisations could improve in the future. Furthermore, this study lacks a large sample of participants and uses only qualitative data. It was necessary to use qualitative data in this study in order to get an in-depth look into how the RCCCA specifically operates, and because time constraints limited how many would-be participants could be engaged with. Future studies can use the findings of the current research as a basis for more qualitative work, or even to help with quantitative analyses of larger sample sizes.

Conclusion

In all, the findings of this study show that the RCCCA is operating at a very satisfactory level. Based on the responses given by the participants, the wide range of services the club offers and the familial environment which has been fostered since its founding in 2015 provides an ideal platform for children to grow and develop into high functioning teenagers and adults. In addition, the RCCCA is providing parents with a unique outlet in order to help deal with the tribulations and stresses caused by raising a child with autism. The financial and emotional strains are being lifted by the involvement of other parents and the community that has grown through the years. However, there are certain restrictions, which are being caused by funding issues. There is a need to expand the premises in order to allow the Club to grow so that waiting lists can be decreased and extra services can be added. Furthermore, there is a great desire among all stakeholders to see the services and therapies offered by the club to be offered simultaneously from the same location. An increase in funding would evidently go a long way to easing these restrictions and helping the RCCCA to achieve its objectives sooner. However, in summary it is clear that the Rainbow Club Cork Centre for Autism is providing a hugely positive service for children with a diagnosis of ASD and their families.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Boilson, A. M., Staines, A., Ramirez, A., Posada, M., & Sweeney, M. R. (2016). Operationalisation of the European Protocol for Autism Prevalence (EPAP) for autism spectrum disorder prevalence measurement in Ireland. *Journal of autism and developmental disorders*, 46(9), 3054-3067.
- Department of Health (2018). *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies*.
- Duvekot, J., van der Ende, J., Verhulst, F. C., Slappendel, G., van Daalen, E., Maras, A., & Greaves-Lord, K. (2017). Factors influencing the probability of a diagnosis of autism spectrum disorder in girls versus boys. *Autism*, 21(6), 646-658.
- Gau, S. S. F., Chou, M. C., Chiang, H. L., Lee, J. C., Wong, C. C., Chou, W. J., & Wu, Y. Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 263-270.
- Hsiao, Y. J. (2016). Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: Roles of parental stress, children's performance, medical support, and neighbor support. *Research in Autism Spectrum Disorders*, 23, 122-130.
- Jones, E. A., Fiani, T., Stewart, J. L., Sheikh, R., Neil, N., & Fienup, D. M. (2019). When one sibling has autism: adjustment and sibling relationship. *Journal of Child and Family Studies*, 28(5), 1272-1282.
- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... & Reynolds, A. M. (2007). The epidemiology of autism spectrum disorders. *Annu. Rev. Public Health*, 28, 235-258.

- Roddy, A., & O'Neill, C. (2019). The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?. *Autism*, 23(5), 1106-1118.
- Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. *International Review of Psychiatry*, 30(1), 40-61.
- The Rainbow Club for Children with Autism. (2020). [online] Available at:
<http://www.rainbowclub.ie/> [Accessed 7 Feb. 2020].
- The Rainbow Club for Children with Autism. (2019). *Children and Youth Education Fund Application Form*.
- Weitlauf, A. S., McPheeters, M. L., Peters, B., Sathe, N., Travis, R., Aiello, R., ... & Warren, Z. (2014). Therapies for children with autism spectrum disorder.

Appendices

Appendix A

Interview Schedule 1: Former Service User

1. What have you gained from your involvement with the Rainbow Club over the years?
2. What do you believe are the most beneficial programmes run by the Rainbow Club and why?
3. In what way, if any, do you believe the Rainbow Club could improve in the future?
4. The current aim of the Rainbow Club is, in the near future, to provide all of their services under one roof, meaning that therapies, sports groups, social groups etc. will be available in one hub of education, care and support. As someone who has availed of some of these services, what effect do you see this having for children in the Rainbow Club?

Interview Schedule 2: Mother of a child in the Rainbow Club

1. What have you and your child gained from your involvement with the Rainbow Club over the years?
2. What do you believe are the most beneficial programmes run by the Rainbow Club for you and your child and why?
3. In what way, if any, do you believe the Rainbow Club could improve in the future?
4. The current aim of the Rainbow Club is, in the near future, to provide all of their services under one roof, meaning that therapies, sports groups, social groups etc. will be available in one hub of education, care and support. As a mother of a child who uses some of these services, what effect do you see this having for children in the Rainbow Club and for you and other parents of the Club?

Interview Schedule 3: Employee of the Rainbow Club

1. Over the course of your employment here, what do you think children and parents gain from their involvement in the Rainbow Club?
2. What do you believe are the most beneficial programmes run by the Rainbow Club for children and their parents and why?
3. In what way, if any, do you believe the Rainbow Club could improve in the future?
4. The current aim of the Rainbow Club is, in the near future, to provide all of their services under one roof, meaning that therapies, sports groups, social groups etc. will be available in one hub of education, care and support. As an employee, what effect do you see this having for children in the Rainbow Club and do you feel this will have an impact over how well you will be able to do your job?

Appendix B

Interview 1: Former Service User

1	Researcher: Anyway, thanks for agreeing to take part, I really appreciate it, dude. So, we'll start off. How long have you been in the Rainbow Club actually?	
5	Interviewee: Eh, well, I've been volunteering now about a year... ah... a year and a few months I think, but I used to attend the Rainbow Club myself, I was in the older boys, so the Monday night sessions, the 7-8. I was in there about two years, yeah, about two years.	Attended the club and now volunteers
10	R: Okay, so it only started in about, what 2015? So, were you straight in when it started or...?	
	I: Ehm, I wasn't exactly I was in when I was in fourth year, so I think 2016 I was in so just after.	
	R: Oh okay, just about six months, I'd say.	
	I: Yeah.	
15	R: Right, let's get cracking into this. Eh, alright so what have you gained from your time in the Rainbow Club?	
	I: Eh, would you... Which perspective do you want that from? From attending it or...?	
20	R: From attending it, and then maybe from volunteering. Mostly from attending it.	
	I: From attending... Eh, I would say I got a lot better with my social, sort of, skills. Before, like, I'd, I appear to be very social now but before, probably about five years ago, if you had approached me to ask me to do this interview, I wouldn't have even had said no; I'd have sat in the corner in silence and ignored you.	Improved social skills
25	R: Oh, really?	
	I: I was very bad at talking to people.	Very social now
30	R: Okay.	Would not have talked in the past
	I: So, I was very, sort of closed in on my shell and it took me... obviously from just before I started Rainbow Club to now, so about four or five years to be like this, the annoying me, who's very talkative.	Was very bad at talking to people
35	I: But, I kind of got a lot of experience trying to deal with people. Oddly enough from dealing with the volunteers in there because... not because they're always swapping but because, they change, like, if someone's sick, someone else might pull in. And it was really interesting to see like a variety of people, and even to see the... uh, how would I describe it...	Was very closed off
40	R: The sort of community aspect of it... the organisation?	Is very talkative now
	I: Kind of the community, but it's almost the... I only know, ehm, autism or Asperger's from my perspective and I didn't know anyone else with it for,	Had experience with different people
45		

	until I came by the Rainbow Club. So it let me kind of see what it's like for some of the other kids and if you see me now upstairs (R: Yeah) I've a good relationship with all the kids that are in that class because I've seen them for years now at this point (R: Yeah, yeah), but I got a lot of like...	Learned what ASD was like for others
50	R: Confidence?	
	I: Yes. Confidence was definitely a big thing. I remember I was so nervous, when I first started that I had no idea what I was doing. Like, even, like I couldn't do introductions or talk with people. So, I think when I was... when I first came in, I was... I came in, wandered around the room and just found the... you know the round table?	Knows the kids well
55	R: Yeah.	
	I: And I just sat there for about an hour (R: Okay). And that was my first session, and it was Maria and Andrew, eh they were talking with me. And slowly, it took me a couple of weeks, but they were able to coax me into talking more and kind of since then, I don't know, I've always been working on that. And obviously now I've had some little issues with my conversation skills because I can kind of hold a conversation now.	Has gained confidence
60	R: Well you're doing a good job at the moment	
	I: Yeah! <i>[both laugh]</i>	
	R: I haven't said a word!	
	I: <i>[laughs]</i> Yeah, I kind of talk peoples' ears off.	Didn't know what he was doing when he first started attending
65	R: No, no, but you know what I mean, like?	
	I: Yeah, I've... that tells you how much I've had to go... go with as a change.	Was very shy
	R: That's obviously a huge jump in the last four and a half years.	
70	I: Oh, definitely, like, you could ask maybe my mam, but even Kate and Des, they know me from the start and when they saw me like, I did talk, but if I didn't have to I wasn't going to. So, I've had to do a lot of trial and error work with them, and there's even like, little bits, now that I'm volunteering there. Like, they took over the café only last April, I believe. And I was volunteering in there, now I'm working in there. But even though I had the job they said like, they had to bring me for a formal interview and stuff.	Slowly came around to talking
75	R: You obviously got the job <i>[both laugh]</i> .	
	I: Oh! Yeah, they gave me a lot of like, practice with that, just interacting with people. So... I kind of got a lot out of it.	Can hold conversations now
80	R: That actually leads on well to my next question, because I was going to ask you what are the best programmes... what are the most beneficial	
85		Has made a big change in conversation skills
90		Would not talk unless he had to
95		Now is employed by the club
		Was able to practice communication skills

		programmes run by the Rainbow Club, for you, as a former service user? You know looking back on your own time until now.	
100	I:	Yeah, I'll say I wasn't, eh I wasn't taking a lot of the services themselves; I was mainly just always in the social club. They're always offering me to like, come and join... they had, obviously they had the sports club, but they had other services like eh, speech and	
105		language therapists and the play therapy.	Social club was most beneficial for him
	R:	Did you avail of any of them yourself?	
	I:	Ehm, I didn't, mainly because I had kind of gotten those when I was a lot younger and they were good, but I know they're not the kind of things I need help	
110		with.	
	R:	Do you say like, the social clubs were the most beneficial because that's what you struggled with?	Would have used other services if they were available
	I:	Yes.	
	R:	So, it's very much pertinent to each child, one child might need a speech and language therapist. For you it was... you just needed to be around people and	
115		learn to engage with people	Was able to work on what he struggled with
	I:	Yes, it was completely like –	
	R:	Sorry, I don't want to be putting words in your mouth now!	
120	I:	Oh, know you're right it's down to, like, I know like all the kids have autism here, one way the other. But they all have... I always call it the checklist, other people call it the umbrella, someone else calls it the	
125		list.	
	R:	I haven't heard of this.	
	I:	We all have different ways of describing it, but I would describe it as like, there's a checklist of every single condition you could have with autism, and	Each child's autism is different
130		everyone has a slightly different checklist of what boxes they hit. And with mine, a lot of my issues did come from like, the social stuff and a lot of like, confidence and self-esteem kind of work. So,	
		because, obviously I was so nervous, I only really	Each child has different symptoms
135		took part in the social side of things, but I know if Rainbow Club was around when I was younger, I would have been in say, the sports club that's on	
		now. I would have been in that I know for a fact, because my mam through me into doing rowing for a	Each child needs services tailored toward them
140		while so that I would develop that kind of stuff.	
	R:	The motor skills and confidence and even the social aspect of rowing, teamwork and stuff.	Would have used Rainbow Club services when younger if they were available
	I:	Oh, yeah. But ehm, no I know if it was around before I would be in like, the sports club and more of like,	
145		the play therapy and those sort of services.	

	R:	Cool, alright. Ehm, so what way, if any, do you think the Rainbow Club could improve in the future?	
150	I:	I'd almost say... almost getting bigger is kind of the best way to describe it, because they seem so limited here.	
	R:	Space-wise, or just employees or...?	Rainbow Club needs to get bigger
155	I:	Well, I'd say kind of in most respects because they do have... obviously they've hired, ehm, ehm, employees that are working upstairs and you know like...	Limited at the moment
	R:	Therapists and things and...	
160	I:	Yeah, and there's the volunteers and even people come in doing like training and... like many of the students that come in just to see the place and help out. And it was... it's really good but it's that sort of, because it is still so new, it is still being held together by the community around this place. If... I know they'd probably need like more managers and	
165		probably more employees because I remember when I was coming in there was a, like, fairly heavy waiting list; and the main reason I was able to get in was because I was my age group, I was 16? 17? And just because my age group didn't have any services applied to them by the HSE or the government.	The club is being held together by the community
170	R:	There's something like, 258 children on the waiting list at the moment.	Heavy waiting list
	I:	Oh, yeah, and it's because that... it feels like they need like ah... a massive push just to expand it. I feel like they do a lot and they do help with so much but where they are, they're so limited in their resources	More space for teenagers
175		(R: Yeah). Like, even, eh, we put on sensory Santa, and we put that on in the hall and that was fine, but we had to take that down every year, and put it back up, and then take it down again (R: Okay). And doing that and having like, most members of the community using that hall as well like, if there's their own premises they'd be able to do like, a sports hall on their own.	Need a push to expand
180			The club does a lot with a little
185	R:	Leads into this well. So, the aim of the Rainbow Club is, in the near future, to have, ehm, all their services provided under one roof, so to have sports groups, therapy groups, social groups etc. in one hub of education, care and support, what impact do you see that having on the Rainbow Club in the future, as a former service user?	Shared space with community centre
190			Need their own premises
195	I:	I see that having a massive, ehm, how would I describe it? It's going to be a massive help; I would say straight off the bat. If they can, sort of, having everything together in the one area, like, how would	

		I...? My words aren't working properly at the moment [<i>both laugh</i>].	Would be a massive help
	R:	Been there.	
200	I:	Ehm, they... like I said they need that sort of push just [<i>pause</i>] it's so limited what they do now that they have sort of aspirations to get a larger complex almost, so they can provide all of the services at the same time. It will be a massive improvement. The	The club needs a push
205		only thing I'd be worried about is that they can keep, sort of the increase in space, like, in proportion to the increase in staff. That's the only thing, just because, obviously like I said there are so many volunteers coming in and like...	Providing services under one roof will be a massive improvement
	R:	Well I mean, if the funding increased, well then, the revenue would increase.	
210	I:	Yeah.	Need trained staff for future growth
	R:	You know with people paying so. Then there'd probably be more staff hired, but it's a legitimate concern.	Reliant on volunteers
	I:	Yeah.	
215	R:	That it could outgrow itself	
	I:	Almost, yeah, and it's just that kind of worry that... just because being here for so long I've seen so many different ehm...	
	R:	Well as the service gets stretched, the quality drops.	
220	I:	Yeah.	
	R:	And then you could... yeah, yeah, it's a legitimate point actually I didn't really think about it that way	The club must not outgrow itself
	I:	And it's just one of those little things that like... even the simple stuff because I've been here for so long	
225		I've seen so many different kinds of, like, volunteers and workers and because the employees have been, like trained and what not in how to handle the children and a lot of them know most of the children; it's interesting to see that an issue could arise where	Quality of service must be maintained
230		so many students or people could be coming in with what I'd describe as like, a college of book education on how to deal with autism because I see this... I see how they react to some of the children upstairs and while a lot of the points are really good, and they	
235		should take those lessons from the colleges, there's some limitations and differences.	Trained experienced staff are needed
	R:	You don't know until you're there.	
	I:	Yeah I've seen how some of them react to actually working with the kids and it's very entertaining to see them [<i>both laugh</i>], ehm... one young fella, I won't give his name, but he was bothering two of the volunteers just trying to annoy them and he got the reaction he wanted out of them. But I know him years now, and so when he came over to me I was in no	Experience is key when working with children with ASD

245	way phased and just because I have the experience of I know what to expect [<i>sic</i>] because it's not just a case of you're dealing with an autistic child, you're just dealing with a normal child as well (R: Yeah) because they'll do their usual thing to get a rile out of you one way or the other.	
250	R: Kids are kids!	His experience helps him handle situations easier
	I: Oh, yeah. Autism or no they're still evil most of the time but it's...	
	R: So you would say that if it's going to grow, if it's going to get bigger, if we're going to have more space, we got to have trained staff as well, (I: Yes) we got to have more of them, we got to fund that, it's equally as important as getting the space.	
255	I: I would say so because –	
260	R: And what do you think – sorry just one more question. What do you think's the benefit of having everything together so, having your speech and language therapist there, having your full time OTs, having your music groups, social groups all in the one place rather than...?	The club must grow proportionately
265	I: I'd say mainly, it's sort of... if you've seen a lot of the families like, now since I'm working in the café that the club owns, I see a lot of the families, and the fact that in most of those families, it's never just the one child who has something it's usually one or two and for a couple of families more than two.	
270	R: Yeah there's some with three in the club.	The club aims to help entire families
	I: Three and four every now and again, and I can see that, even if just say like, the sports hall that's on at the moment; if that the music groups and the social clubs were all on at like, the one time, then kids that like... older kids that aren't going to be needing something like the sports club and they come in they can go instead to the music, or the social. Whereas younger kids, if they have no interest in music, they can go to either the sports or the social club. It's trying to give the options for their development.	
275	R: And then let's say there's a child who needs play therapy; well we're going to send him to the play therapist while my other son goes to the sports club?	Families often have multiple children with ASD
	I: Yeah, because I understand the pressure it puts on families when they have to be out here for like, say 2-3 for one child, and then they're not in until 5-6 for another session.	
280	R: It's disruptive for the child as well, having to go back and come back in...	Different children can use different services simultaneously
	I: Going everywhere and sometimes I can see and obviously I've seen how some of the kids have	Can ease stress families are under
285		Give options to children to aid development
290		

295	meltdowns and it's... I can see how much of a relief it could be to have it all together.	Families are currently under time pressure
	R: Alright. Look, that's brilliant man, thank you so much for helping me out.	
	I: No bother!	
	R: I really appreciate it, I'll end it there, alright, thank you!	Children can be perturbed by time constraints

Interview 2: Employee of the Rainbow Club

1	Researcher: Okay, hello, Ann.	
	Interviewee: Hello, Mark.	
	R: Alright I'll start with the first question anyway, so Rainbow Club?	
5	I: Working here since September 2019. Volunteering here since the Summer of 2016.	
	R: 2016, so, nearly four years?	
	I: Yeah, but employed for the last six months.	Employed 6 months
	R: Okay, excellent, good. So, over the course of your employment and volunteering here, what do you think children and parents gain from their involvement in the Rainbow Club?	
10	I: Well, over all my time here I suppose the kids gain a social group, a place that's for them, it's their club, it's not... you know other children have ballet, have [sic]... whereas this is theirs. It's where they can be themselves and why they can socialize with their own peers. And for the parents, giving their children... to be able to have somewhere like that to go	Kids gain a social group
15	R: It gives them a break you mean?	
	I: Yeah but they, no, [sic] for their kids to have a social group, to have a group that's theirs, but for the parents to have their hour of plus to meet other parents that are going through similar situations.	It's the kids' own group
20	R: Yeah that's an eh, interesting point because... eh what do you think the benefit of that is in terms of it gives a sense of unity between the family members and things?	Parents meet people in similar situation
25	I: If one person is struggling in one area another person might have went through it like we have a lot of new parents coming on board at the moment that wouldn't know where to go for help, who to ask for the help, the struggles with trying to get into schools, there's so much unity with the parents; they're giving each other advice, help, a shoulder to cry on as well.	People help each other
30		Parents need help
35		Parents share similar struggles

	R:	Okay, okay, that's good.	Shoulder to cry on
	I:	And they've become – (R: Sorry, go on.) the parents have become great friends.	Parents become friends
40	R:	Okay, so it's become a support circle for families, so it's very much it's <i>[sic]</i> more than just for the child.	
	I:	It's basically for the whole family.	
	R:	Ah, okay, okay, ehm so following on from that, you've talked about the groups, but what do you believe are the most beneficial programmes run by the Rainbow Club for children and their parents, and why?	For the whole family
45	I:	Well everyone really is beneficial...	
	R:	There's a lot of them I suppose <i>[Both laugh]</i>	
	I:	Yeah, like their social groups just for them to have their social club, it, but it's <i>[sic]</i> great like we're trained up from the speech and language therapist, like, they give us ideas of how to work with the kids up here as well, do you know like from Laura, (R: Okay) so we'd interlink with her like, if... <i>[sic]</i> she works with a lot of the children up here as well, so she'd say to us, like... give us ideas "oh I know that child" so do this, do that with them (R: Mmm) so for us up here to be able to work like that is great but they also then have the speech and language therapist, they have music therapy up here, the OT, play therapy, art therapy everything really is beneficial for them.	Lots of beneficial programmes
50			Social clubs are great
55			Employees work with SLT
			Work specifically with each child
60	R:	And as an employee, you are able to take the bits from, say the play therapist has told you, what a speech and language therapist has told you, or you might see a child in a music group doing something and you can then bring that to the club when they're here for that hour every week.	Lots of different therapies available
65	I:	Yeah, which is great, or for us as well like, we might notice something about a child and we can refer them to go to, (R: Oh, yeah?) to go to <i>[sic]</i> the play therapy.	
70	R:	Oh, so you always have a professional hand there for you to always help you out I suppose (I: Yeah), yeah. Okay, ehm, right so in what way, if any, do you believe the Rainbow Club could improve in the future?	Communicate with other factions of the club
75	I:	Hmm, well really <i>[pause]</i> ... more, like it's the only place in Cork, only place in Ireland I think, like this. For this to become bigger, there's so many children still on the waiting list, like since we started being employed, like as a volunteer here, we always had the flow but as volunteers like, I thought, when I was in my old job and I'd come over after work, there was days when I used to be tired and I might text Jane and I'd say "God like, I really can't come in today, I've had a tough day at work" for me to like, going forward to be able to employ more people, to have a sturdier...	Unique service
80			Become bigger
			Many children on the waiting list
85			Volunteers could be tired

	R:	Do you mean like employ just to bring more expertise in or –	Employees are sturdier
	I:	Well workers like myself, so they can bring in more children.	
90	R:	Oh, okay so there's just more attention being given to children essentially.	
	I:	Yeah and they're trying to make that, you see, about making another room come available, so there'll be another room for another social group to run, like just to have more employees in there	More workers for more children
95	R:	And how has [<i>sic</i>], and you started off as a volunteer and now you're an employee, do you think, with more employees, as opposed to volunteers who are obviously trained to work here.	Making another room
100	I:	Oh my God, the volunteers are, they're the core of the place (R: Yeah, yeah), and more volunteers, like a lot of the students who have come through here are now, that I've had over the last six months, are now after filling out all their vetting, so they should all be volunteering through the summer so it'll be great (R: Brilliant) now, yeah. So, there's loads of them.	More employees needed
105	R:	And do you think space is an issue at the moment?	Volunteers are core
	I:	Yeah, a big issue as you can see for yourself.	Students become volunteers
	R:	Yeah, I mean, yeah just seeing, just walking around here you can see that	Loads of volunteers
110	I:	Yeah, like, this... this room they couldn't have more than five children in this room, whereas when they get bigger, they could have ten children in a room with two people.	Space a big issue
115	R:	Yeah, and the more space the more children, the less on the waiting list.	Bigger rooms allow for more children
	I:	And that's what it's all down to really, they want to be able to help everybody.	
120	R:	Okay, okay, perfect. Alright, so, the current aim of the Rainbow Club is, in the near future, to provide all of their services under one roof, meaning that therapies, sports groups, social groups etc. will be available in one hub of education, care and support. As an employee, what effect do you see this having for children in the Rainbow Club and do you feel this will have an impact over how well you will be able to do your job?	Want to help everybody
125	I:	Ehm, eh [<i>pause</i>] the Rainbow Club...	
	R:	Sorry it's a long question [<i>Both Laugh</i>]	
130	I:	It's going to be wonderful, ehm, to have everything under the one roof, like for, the aim of Rebecca is to have like a counsellor here for parents, sibling groups like where they can do after school homework, so everyone you know, if their sibling was up here, they'd have an area where they can sit down and relax	Wonderful to have everything under one roof
135			

	and chill. Now, they do have the café and stuff at the moment, but ehm, they're employing a speech and language therapist, I don't know if you'd been told about that, Hayley's going to be full-time here.	Lots more resources for whole families would be available
140	R: Yeah, and at your disposal.	
	I: So, to have it all here where the kids are comfortable, but... where the kids are comfortable coming into club, like ehm, we had one child the other day who's going to speech and language with Helen, but when	Already employing a full-time SLT
145	she comes to Rainbow Club it's like, she wants to go to Rainbow Club, into her group. So, we had to bring her in for ten minutes to Rainbow Club and then transition her down to speech and language (R: Yeah), but like she's so comfortable in the Rainbow Club it's like she's at home.	Kids are comfortable
150	R: And this is, kind of the positive, like that's the direction you want to be going in the future.	Kids crave structure
	I: Whereas if she was going somewhere else for speech and language outside of the Rainbow Club, I don't know how they would transition it down.	Children comfortable in Rainbow Club
155	R: It's, eh, and that need to go somewhere else is what happens when you have these waiting lists?	
	I: Correct, the need for that... will mean that it'll all be here, so it'll all be in the Rainbow Club, where they're you know...	Different places cause discomfort for child
160	R: So, like, they'll just need to walk into the next room in order to go to speech and language therapy	Waiting list causes discomfort
	I: Yeah, and it'll all be together.	
	R: Do you think that'll help you, just because I was thinking like... a bit about your role as an employee and your job.	Children are comfortable in the Rainbow Club
165	I: For my job? Well my job is just, like, the social groups (R: Okay), like I manage the social club, but like I won't have much, like I won't be managing the speech and language that'll be Sarah doing all that but for me	All together
170	it'll be a great benefit that I will have more access to the speech and language therapist, I'll have more access to the different areas that are going on.	
	R: Do you think that, in terms of, if maybe you're seeing a child struggling, ehm, or just a behaviour that you think you want to know more about that you can have an OT on site or speech and language therapist on site and you'd say "listen he's presenting with this type of behaviour or that type of behaviour, should I be worried, should I do this should I do that"	Benefit of communication with therapists in the club
175		
180	I: Yeah ask them to come up. Say, "Could you come up and have a look for five minutes at the behaviour in the room"	
	R: Rather than –	

185	I:	Having... the child would be out in a different area that I don't have access to or ask them how they're working with that child.	Communication will be easier under one roof
	R:	Yeah, rather than having a speech and language therapist not on site, and obviously you'd have to	
190		phone call, you'd have to wait a couple of days, they can't see the child immediately.	No access to child if in different area
	I:	And it's all confidentiality as well, like. You know, that's another thing	
	R:	Yeah, that's another big part actually yeah. Ehm, just	
195		going back, how do you see the extra space actually improving the... the... trying to find the right word here. The quality, I suppose of the therapies being provided, is that being hindered at the moment or do you think that... –	Confidentiality important
	I:	Well at the moment, this space here is limited, it's very	
200		limited, like the speech and language therapist has a little Portacabin there, the play therapist and the art therapist share. I think like they're aiming to have a specific music room, but whereas at the moment	Limited space
		they're using this room for music. Do you know, and	
205		then there can't be a group run later in the evening in this room, because it's music is in here. So, it would all free up more space to bring in more children and that's all they want they want every child to be able to be helped not have a waiting list where you have	Rooms are shared for different functions
		parents crying out for help	
210	R:	So, you think, ehm, the best way to do that is you have one room for one function and that's how it is, you don't have to cross over, "we'll use this room for..." –	More space for more children
	I:	There's no crossing over like, we have our social	Parents need help
215		rooms, they'll be for social groups.	
	R:	Yeah so, the social groups obviously use these rooms as well, but you'd like to take that away, <i>[laughs]</i> not take that away but just make it its own room	
	I:	Yeah like the social groups would be what we'd do but	There should be no cross-over between rooms
220		like then they'd, they might use one for speech and language, but, not for speech and language but for their music. Eventually, we'll have another social room again, so they'll have more kids brought in and then it won't be affected by, "oh music is on Tuesday	
225		nights and Thursday nights so the teens can't be in them nights <i>[sic]</i> ", like you can have more teens in them nights because the music will have their own room and it'll also be going through during the day.	Not enough rooms
	R:	Alright. Brilliant, I think that's every question covered,	Clashes are being caused
230		thanks much I'll end it there so.	
	I:	No problem, thank you.	

Interview 3: Mother of a child attending the Rainbow Club

- 1 Researcher:** Alright, Michelle, thank you so much for agreeing to take part. You're doing me a huge favour here. Ehm, so, look we'll get started into it. Just, firstly, you have how many children in the Rainbow Club? Is it two?
- 5 Interviewee:** No, one in there.
- R:** Just one is it?
- I:** Yeah, yeah
- R:** Oh, sorry that's eh... and how long has he been attending for?
- 10 I:** Ehm, four years. Child has been attending for four years
- R:** Four years (**I:** Yeah), okay so he's been here since the early days really, okay.
- I:** Mmm, about three and a half years.
- 15 R:** Three and a half, four years. Alright, and what age is he actually?
- I:** He's nine in May, so he's eight now.
- R:** He's been here since he was four years old. Started attending at age four
- I:** Yeah.
- 20 R:** Okay, ehm, alright so, we'll start away. What have you and your child gained from your involvement in the Rainbow Club over the years?
- I:** Ehm, we've gained a lot, it's been a long time so, ehm, when Ian, my son, was younger, ehm, he was non-verbal when he first came to the Rainbow Club. Ehm, he had no social skills at all. Ehm, he just used to line things up and stim, ehm that was kind of his basic daily routine. Ehm, when he started, at the start, he started [*sic*] with one hour a week in a social group. Son had no social skills
- 25 He's now [*sic*], he now does art therapy as well and sports on a Saturday. Ehm, he's gained a lot of confidence in, ehm, interacting with other children and he's come on leaps and bounds his speech ehm, he started speaking and the girls in the Rainbow Club, the volunteers, kind of worked with that, ehm, and they encouraged him to tune into playing, he's now able to play with other children, ehm, and get involved with groups rather than avoiding them. Ehm, he's... In the Rainbow Club as well he actually, ehm because they have a sensory room there he's [*sic*], he kind of became more aware because he started at such a young age when he needed sensory breaks himself, ehm, with the volunteers in there encouraging him to use the sensory room. So now he actually knows already, he's only eight, but he knows when he needs to withdraw from a setting and go into a sensory room. Ehm, he's gained good conversation skills in there, ehm, he's become more confident in who he is, especially as he's heading towards like the tween age-group [*laughs*].**
- Started with the social group
- Gained confidence
- Speech improved
- Volunteers worked on speech
- Can now play with other children
- More self-aware
- Takes sensory breaks
- Good conversation skills
-

50	He... with the sports then that he does on Saturdays, his balance has come on an immense amount, he's becoming really good at working with a team. Ehm, he... his coordination as well has obviously come on a lot.	Improved balance Can work in a team
55	R: What about yourself, as well? I: Myself! R: It's okay to talk about yourself, like! <i>[both laugh]</i> I: Ehm, me, ehm... I think I actually owe a lot to the Rainbow Club. Ehm, when he got diagnosed there	
60	wasn't really much follow-up, he never saw a psychologist. Ehm, he didn't eat, he didn't sleep, he didn't ehm... he didn't talk, so it was very tough for me at the start. Ehm, with the Rainbow Club be...	Had no help at diagnosis Was tough at the start
65	<i>[sic]</i> you know, as soon as I got into the Rainbow Club, the parents in there; they like, just kind of took me in under their wing. Ehm, and Amy as well like is... she's outstanding, like the amount she knows (R: Yeah). Like, she taught me a lot and she was kind of there for me. They're there for you at all levels like,	Parents took her under their wing Learned a lot about autism
70	any problem you have and I didn't get any of that obviously with the HSÉ, ehm, nothing really to talk about, like as regards we never got any booklets, we never got any guidelines, didn't really get much. Ehm, so everything that I learned was from Amy in the	Wasn't getting help from HSÉ
75	Rainbow Club. Ehm, I became confident in how to manage my own child, which is, you know, what you need. Any tips and things that were working for him you know, I was told about and able to carry that through to at home.	Became confident in how to manage child Was given tips from other parents
80	R: Yeah, okay. So, what do you believe are the most beneficial programmes run by the Rainbow Club for you and your child and why?	
	I: Definitely the social group. I know he... he attends art therapy as well and sports, but definitely the social	Social group most beneficial
85	group.	
	R: It's kind of a unique thing for the Rainbow Club is it?	
	I: Yeah because everything you see out there, like, everything's revolved around their education and their schoolwork and especially when it's a high-	Social group about being who they are
90	functioning child when they're extremely intelligent and it's the social skills that are lacking. You know, just basic awareness of other people around them, and even their spatial awareness and everything suffers, and once they're doing well at school they don't	Social groups help with social skills
95	really... you know, they're considered fine, you know which is a big thing I think, ehm and the Rainbow Club really helped that in the social group. Like, he looks forward to it every week, every single week and he knows he's going, and he can rely on it, it's his	Children are considered okay if good in school

100	safety net. Eh, he's... he... it's so funny, he stims a lot more in there as well because he's excited.	Looks forward to Rainbow Club every week
	R: He's enjoying it.	
	I: Yeah but he's allowed be who he wants to be... it's like he knows already that... in the environment	
105	around him in school he still can't be that.	Can be who he wants to be in Rainbow Club
	R: It's less restrictive, that's kind of the thing about the social clubs isn't it?	
	I: Yeah, and even with the Rainbow Club because there are people there as well, volunteers that are also	School more restrictive
110	autistic, autistic adults and things as well it's just more comfortable for them, you wouldn't think that they'd pick up on it, the kids, but they do, you know?	
	R: Yeah, and... you said it's kind of a place where he can be himself, what do you really mean? Like... could	Rainbow Club is comforting for children
115	you just elaborate on that a little bit more, I think it's an interesting point to hear you talk about because I don't really understand obviously.	
	I: Okay, he spends a lot of time, ehm, kind of holding back who he is you know, the "him" that I know. Ehm,	
120	at home like, his interests and his hobbies, like his obsession with the universe, well not obsession but his vast intelligence and everything about the universe.	Child spends time holding himself back
	And when he's at the Rainbow Club he can just be him. You know, nobody judges him, I think what	
125	people forget with autistic kids is they're really intuitive and like, he knew from a young age that he was different, ehm, even though he wasn't able to communicate that but when he's at school, even in the mainstream class... he's in a unit but still, he can't be	Can be himself at Rainbow Club
	– he's not himself in there because... I don't know is it the structure that they have to stick to?	Can't be himself in school
130	R: Just the environment, more restrictive?	
	I: Yeah, yeah, yeah, and in the Rainbow Club...	Can't be himself in rigid school structure
	R: There's kind of, more social norms in schools, I think, being compared to the Rainbow Club or... you can do whatever you like, you can play with trains, or... you can just chill out if you want to, you know?	
135	I: And it just doesn't feel like he's judged, like I actually think that's a big thing, you know?	
140	R: Alright, perfect. Eh, okay I was just going to ask you now, ehm, in what way if any do you believe the Rainbow Club could improve in the future?	Not judged in Rainbow Club
	I: Well, I suppose it's what we all say; they need expansion, of course. Ehm, people... like... obviously	
145	like more rooms and everything's cluttered in, of course and obviously it would benefit the kids if they had more free space... that's... you know? Ehm, people becoming more aware of the Rainbow Club, again, you know more volunteers and things like that.	Rainbow Club needs expansion Everything is cluttered

150	Ehm, definitely something that I'd love to see is something for the siblings as well, if it's supporting families.	Children need more space
	R: That's interesting now.	
	I: Yeah, I know they want some <i>[inaudible]</i> alright.	Needs to be more awareness of the club
155	R: Does your son have a brother or sister, does he?	
	I: What?	Would benefit from sibling groups
	R: Your, ehm –	
	I: Yeah! Yeah, he has a younger brother and my own brother has ehm –	
160	R: And does ehm... does Ian's brother have a diagnosis of ASD?	
	I: No, no.	
	R: Okay so he's neurotypical.	
	I: No, he has no diagnosis of anything, but I have a brother myself on the spectrum (R: Okay) and I know what it's like growing up being the only sibling. And I think that's a thing that's overlooked sometimes, mothers and fathers are supported and sometimes, and the child is supported but the sibling is often forgotten about and like, they do grow up with a lot of... a lot of issues facing them on the back of...	Can be difficult for siblings of children with ASD
165		
170	R: Yeah because of...	Sibling can be forgotten about
	I: Yeah, yeah.	
	R: So, a further space for them to be able to grow and things like that?	
175	I: For the families, yeah.	More space for families needed
	R: So, again a sort of holistic approach.	
	I: Yeah.	
	R: Brilliant, okay. Ehm, so the current aim of the Rainbow Club is, in the near future, to provide all of their services under one roof, meaning that therapies, sports groups, social groups etc will be available in one hub of education, care and support. As a mother of a child who uses some of these services, what effect do you see this having for children in the Rainbow Club and for you and other parents in the Club?	More holistic approach needed
180		
185	I: It's fantastic, it would be absolutely fantastic.	
	R: So how do you see that benefiting?	Providing services under one roof would be fantastic
	I: In every way, first of all for the child, ehm, it's a place they're familiar with, a place they know. Ehm, when you... when you're waiting for appointments now it's just desperate you can be sent from East Cork up to you know, miles and miles away.	Services need to be in familiar place for child
190	R: Yeah, don't they do it by regions and stuff isn't it?	
195	I: Yeah, and then the child is going somewhere they're not comfortable with as well (R: Yeah), you know, so it's just not going to work from the start. Ehm, so having everything in one place will be outstanding. It	Services are spread out around the country

200	would really work for everyone, ehm, especially the children.	Children shouldn't be where they're not comfortable
	R: Just in terms of ehm, it would provide like, a comfort as well for children wouldn't it? Really, that they... They'd be able to go to the same place to do their	
205	therapies or just go to the social group.	
	I: And then you have the parents then as well who will be around other parents, see familiar faces. You know, comforting for the parents too.	
	R: Yeah, it's a very familial aspect... talking about	Parents should be around other parents
210	ehm... where does that, I like, that's not something I'd ever really... I'd heard about that ethos of the familial support in the Rainbow Club, but I'd never heard somebody talk about it like you.	
	I: Yeah, I think it's... it's vital especially when people are going through things they're not... they don't feel fully knowledgeable about, they feel scared about.	
215	You know, scared about the child's future, ehm and when they meet other parents in the same boat and are able to just talk to them. It's actually just completely undervalued, having that familiarity.	Familial aspect is vital to Rainbow Club
	R: Just having people who have been through what you're going through as well you know, it's...	Parents in similar situations help each other
	I: Yeah, yeah, exactly.	
	R: I mean, would you say it's a pretty unique experience growing up [<i>sic</i>] with a child with ASD, ehm, kind of something only other parents with ASD [<i>sic</i>] would understand?	Familiarity helps parents communicate
225	I: I think so yeah, because there's tiny little things that you take for granted with a regular child. Ehm, like, yesterday, my little fella, he said he wanted to go out and play, and like I started crying because [<i>laughs</i>] you know?! (R: Yeah) A regular eight year old you wouldn't even take any notice of, but the fact "I want to go out and play" is a big, big thing.	Child now wants to engage in play
230	R: It's a huge step, yeah.	
	I: Yeah, so just to hear that. All you want for them is independence and, you know, to be able to make choices for themselves.	Engaging in play is a big step
	R: Awh, that's lovely [<i>both laugh</i>].	
240	I: One other thing as well about the Rainbow Club...	Independence is the goal for children with ASD
	R: No, go ahead, anything!	
	I: Sorry now just to say, the kind of... after they turn eighteen is another big thing, you know when children turn eighteen and they're finished in the Rainbow Club, you know where do they go afterwards you know, like... follow on adult groups would be fabulous in there as well.	
245	R: Yeah, just in that expansion.	Follow-up groups for children after they turn eighteen needed
	I: Yeah.	

250 R: Yeah, alright, that's everything so! That wasn't so painful [*both laugh*], thank you so much!

I: I never shut up, I'm sorry [*both laugh*].
